the revolution starts at home

CONFRONTING INTIMATE VIOLENCE WITHIN ACTIVIST COMMUNITIES

EDITED BY
Ching-In Chen
Jai Dulani
Leah Lakshmi Piepzna-Samarasinha

PREFACE BY
Andrea Smith

south end press
BROOKLYN, NY :: BOSTON, MA :: READ. WRITE. REVOLT.

Selection, compilation, and introduction © 2011 by Ching-In Chen, Jai Dulani, and Leah Lakshmi Piepzna-Samarasinha
Preface © 2011 by Andrea Smith
All individual pieces © 2011 in the name of their respective authors.
All rights reserved.

First edition, 2011

Any properly footnoted quotation of up to 500 sequential words may be used without permission, as long as the total number of words quoted does not exceed 2,000. For longer quotations or for a greater number of total words, please write for permission to South End Press.

Cover art: Cristy C. Road
Cover design: Benjamin Shaykin
Page design and production: Jocelyn Burrell/South End Press collective
Printed with union labor in Canada by Transcontinental Printing

Library of Congress Cataloging-in-Publication Data
The revolution starts at home : confronting intimate violence within activist communities / edited by Ching-In Chen, Jai Dulani & Leah Lakshmi Piepzna-Samarasinha. —1st ed.
p. cm.
Includes index.
ISBN 978-0-89608-794-1 (pbk. : alk. paper)
1. Intimate partner violence. 2. Same-sex partner abuse. I. Chen, Ching-In, 1978– II. Dulani, Jai. III. Piepzna-Samarasinha, Leah Lakshmi, 1975–
HV6626.R485 2011
362.82'92--dc22
2010054160

South End Press gratefully acknowledges the major institutional support of Medgar Evers College of the City University of New York for providing a physical and intellectual home for the world of independent publishing.

South End Press
Medgar Evers College
1650 Bedford Avenue
Brooklyn, NY 11225
www.southendpress.org

18 17 16 15 14 13 12 11 1 2 3 4 5 6 7 8 9

contents

xiii Preface
Andrea Smith

xix Introduction
Ching-In Chen, Jai Dulani & Leah Lakshmi Piepzna-Samarasinha

PART ONE

safety at the intersections of intimate, community & state violence

5 Reclaiming Queer & Trans Safety
Morgan Bassichis

25 Ending Oppression. Building Solidarity. Creating Community Solutions.
Meiver De la Cruz & Carol Gomez
MATAHARI: EYE OF THE DAY

57 It Takes Ass to Whip Ass
Understanding & Confronting Violence Against Sex Workers
a roundtable discussion with
Miss Major, Mariko Passion & Jessica Yee
INTRODUCED & EDITED BY JULIET NOVEMBER

SEEKING ASYLUM

On Intimate Partner Violence & Disability

Peggy Munson

I was lying on my back, holding the container of jerk chicken my current abuser had cooked for me, when I flipped to the Logo channel and saw my *former* abuser's best friend staring back at me from the television screen, microphone in hand. There she was, interviewing queers seeking asylum from oppressive political regimes. But, from me, she had walked away when I approached her seeking my own kind of asylum from the abusive partner who was my only source of caregiving. That day, years before, she hauled his boxes to her truck, helping him move out of the building we shared. At one point when she was alone, I approached her and began to tell her about the abuse. She spun quickly on her heels, leaving me hanging in mid-sentence.

Later, when I was with another abuser, and even more disabled and homebound, I watched her interview then–US presidential candidate Barack Obama

on another channel. They were talking about able-bodied issues that "transcended" race and sexuality: complete abstractions to me. At some point, she did ask him about health care reform, and he leaned forward with an engaging glint in his eye. I knew neither of them could comprehend my situation. For months, I had been trying unsuccessfully to get a telemedicine or home visit doctor to give me an echo cardiogram at home, as I was growing terrifyingly ill yet could not travel to doctors' offices. All I thought about was how on earth I would get care if my abuser left me. Watching her with Obama, I couldn't help but think about social collusion and the forces that had entrapped me.

Social collusion with intimate partner violence (IPV) can start to feel Orwellian, and in my case, this feeling was pretty literal, since my former abuser's best friend had become a prominent voice of the left and people around me referenced her to me all the time. Yet, in my own universe, built on activist ideals, with enlightened and brilliant friends, I could not find anyone to care for me most of the time except for abusive partners. The best friend, in her moment with my abuser, had been only an unwitting pawn, but she was an example of how pervasive civilian dismissal of the disabled really is, by both larger society and left movements, and how easy it is for even the most informed person to ignore violence against us.

Abusive relationships are often difficult to escape. But when inflicted upon a person living with disability, and thus buffered by social ableism and inaccessibility, abuse is often virtually or literally inescapable. In my own life, gaslighting (a term coined from the film *Gaslight* to denote psychological abuse in which false information is given to a victim to make her question her own perceptions) had become not just an abuser's tool, but literal gaslights spewing mercaptan or carbon monoxide or "illuminating gas" injured me too. With my various disabilities, including multiple chemical sensitivities (MCS), total strangers cause me injury all the time by using common products that outgas chemicals just like old gaslights, and abusers have often helped me when the world had left me for dead. (In the years I was dating him, I was already being unknowingly poisoned by actual old gaslights in my apartment, though the gas company did not identify the leak until much later. My MCS had grown worse there, and as a result I spent most days resting on a small futon in a small room.) The day the best friend dutifully hauled his boxes to her truck, my abuser stood on the other side of my window screen and blew cigarette smoke into my apartment to intentionally make me sick.

So one abuser's ally broadcast to my living room in a glowing box was not my problem: it was the masses she represented, and the pervasiveness of both social ableism and inaccessibility. Lundy Bancroft devotes a whole chapter in his book *Why Does He Do That?* to the allies of abusers, who function at all levels of society. "If you are aware of chronic or severe mistreatment and do not speak out against it, your silence communicates implicitly that you see nothing unacceptable taking place," writes Bancroft. "Abusers interpret silence as approval, or at least as forgiveness. To abused women, meanwhile, the silence means that no one will help—just what her partner wants her to believe. Anyone who chooses to quietly look the other way therefore unwittingly becomes the abuser's ally."

Abusive partners have been the same people who often saved my life and gave me caregiving for much of the last ten years, while simultaneously brutalizing me. I found myself, by my late twenties, trapped in a city where I knew almost no one, so sick I could barely leave my bed, unable to move back home due to the severity of my illness, trying to negotiate with ableist strangers over the internet and phone to get love, care, help, anything. The reality was nobody, including my family, wanted the responsibility of taking care of someone with my extreme combination of limiting disabilities, and it was nearly impossible to get anyone to become fragrance free to even meet me, or even to pay people to get fragrance free to run errands for me. I was beaten long before I ever met a batterer. Though my kind, non-abusive partner took care of me for many years before that, when she moved away I was screwed.

For years, I was offered a Hobson's choice: abuse or neglect. My disability seemed a magnet for abusers, and only got lip-service from everyone else. Weighing my options, I tried desperately to figure out which one would enable me to survive in a post-modernity that, once I left academia, began slowly

killing me. The abusive partners were actually more likely to save my life than not having the care I needed would. They were rare in their willingness to offer consistent, reliable caregiving for long stretches of time, whereas other people I met and dated offered other trade-offs for my disability, such as their addictions that made them willing to hang out with someone who could only lie around. The problem was, I was too ill to even date those people without adequate outside care. I needed care from within a close relationship to even date because I got so ill from interacting with people.

Able-bodied activists tend to see my need for a partner-caregiver as a theoretical abstraction, focusing for example on notions of heteronormativity that conflate romantic (heterosexual) partnership with social well-being. However, such an analysis falls flat on the survival issues disabled people need discussed: who is going to help with bathing and toileting the way a loving partner, rather than an unknowing stranger (who might refuse the task), would do? The world of the disabled is more complex than a clean political agenda will allow. My queer disabled friends and I talk about how we get more disability-acceptance from right-wing Christians than from the queer community, for example. Dr. Judith Wallerstein found, in the largest longitudinal study of divorce, that disabled/vulnerable individuals fare worse in terms of care in divorced families (vs. "intact" married families), so that makes an argument that a partnership-obsessed society (queer or straight) might actually benefit many people with disabilities. With intimate care needs, an intimate, lifelong relationship can become a necessity: my survival, for example, often depends on someone having a comprehensive knowledge of my disabilities—something that cannot be easily trained but has to be experienced over time. It is often a chore to get my revolving-door crew of Personal Care Attendants (PCAs) to make a phone call or send a package correctly, let alone take care of the intimate tasks of caregiving, especially when the turnover rate of PCAs is so high.

A relational element seems almost intrinsic to effective care—in my experience, there is something like an oxytocin effect in which those who truly bond to me are the only ones who give care that is actually life-sustaining and helpful, rather than dangerous or not that useful. It's easy for activists to argue academically about social privileges, but I personally wouldn't choose a more impersonal form of cooperative or institutional care (even if it was relatively clean and functional) over the personal model of the Amish, where in-law suites are built into every house because it is assumed that people will take care of their elder relatives. A more socially progressive, cooperative care model could certainly borrow from the Amish, but the problem is, many severely disabled folks can't afford even an hour in a failed utopia. My queer disabled friend told me a story of how she had to lie about why she was sending her uber-religious PCA to buy vibrator batteries so that she could get off with her lover: she had no one else to do the shopping. Another friend, living in poverty and with no other options, had to rely on an offensive, bigoted man for assistance because nobody else would help her, even though she completely disagreed with and was disgusted by his politics. Our lives don't fit a simple political agenda due to the ubiquity of ableism even in the most forward-thinking circles.

I got sick right after leaving Oberlin College, known for its radical activism and coursework geared toward social change, and yet most of my friends after college could not help or care for me except in minor or temporary ways, so imagining a care system based on friendship and activist ideals is hard for me though I may wish for it. A radical revisioning of care is certainly possible, but only if the survival panic of the disabled is truly, deeply *felt*.

To understand how disability functions in Intimate Partner Violence, one has to shelve denial about how deeply inaccessible US culture can be to people with some disabilities. The Americans With Disabilities Act, after all, polarizes disabilities into the "reasonable" and "unreasonable" by using the term "reasonable accommodation" to denote just how far requisite allowances must go. Most people look at dating, or even friendship, the same way. Some disabilities cross a line, becoming—by cultural standards—too unwieldy to accommodate, resulting in a warped and deadly triage of the "reasonably" disabled who get some human rights, and the "unreasonably

disabled" who don't. When the Domestic Violence and Developmental Disabilities Committee of the Wisconsin Coalition Against Domestic Violence and the Wisconsin Council on Developmental Disabilities put together an alternate "Power and Control Wheel" on domestic violence and disability, it didn't fully account for this social reality. The wheel assumes disabled people have freedom or care in society to begin with, which in my experience is a false assumption. For example, it notes that abusers may exercise "caregiver privilege" by committing acts such as "Treating person as a child, servant," "Making unilateral decisions," "Defining narrow, limiting roles and responsibilities," "Providing care in a way to accentuate the person's dependence and vulnerability," or "Ignoring, discouraging, or prohibiting the exercise of full capabilities"—all of which may occur in an abusive relationship. But in my experience, society has already stripped so many living with disability of those rights so thoroughly that abusive partners may play a contrary role of empowering us by, such as in my own experience, getting me adaptive equipment, making food for my special diet that the PCA program won't allow, or taking care of me in the long, drawn-out crashes after medical appointments when I had no other care. If this "Power and Control Wheel" was made by people with disabilities, they were likely more socially privileged than I or most of my disabled friends. The Wheel does note that abusers might "terminate relationship and leave the person unattended," which is more of the danger I have experienced, but the Wheel doesn't account for what happens next, when the disabled person no longer has a consistent partner-caregiver and society abandons its responsibility to protect vulnerable communities.

Random date prospects I met on the internet, the seemingly sane ones, would not give up their shampoo or laundry detergent to meet me. Meanwhile, abusers showed up with alarming regularity. After I broke up with abuser #1, my first date was with someone who came to my house and brought me Indian food, then admitted on the phone the next day she was enrolled in a batterers' program. When I moved to my new house in the woods, hoping to escape the memory of my past abuser, the people I had met on the internet and hoped to meet in person all had issues with my accommodation needs—except the handsome butch who told me she was interested in green building too, and had stood up to her carpentry boss about formaldehyde in building products. Before long, when she was sexually battering, terrorizing, and torturing me, she also made frantic calls to my doctor trying to get me medical care. She cooked my meals and put them in individual containers and froze them. While my PCAs worked limited hours, she came in the middle of the night in a health crisis and stayed for as long as I needed her. By the time I was fully dependent on the relationship, it was winter, and I often needed her to feed me, bathe me, and help me go to the bathroom.

Because my PCA's hours were simply not enough to keep me afloat, my family was far away, and my close friends had all scattered around the country, when I was too ill to relocate, I became an abuser's perfect victim: an isolated, helpless symbiont. When I broke up with that abuser, the first person who seemed willing to get fragrance-free and meet me admitted that her last girlfriend had a restraining order against her. I tried to find someone for a live-work exchange to live in a room in my barn so that I might have extra care, but the one interested applicant also told me she had a restraining order against her from a recent relationship. Lundy Bancroft writes, "Some abusive men seek out a woman who comes from a troubled or abusive childhood, who has health problems, or who has suffered a recent severe loss, and present themselves as rescuers." Here Bancroft is touching upon something much more socially endemic: many disabled people have come to expect abuse, and to expect social service agencies not to rescue them.

"Abusers will offer you that one thing that you need," said the domestic violence counselor, who had agreed to counsel me over the phone. "That one thing nobody else will give you." The language of her organization, like that of the disability organizations, was all about "independence"—transitional housing, independent living. But none of their services fully accommodated people with severe multiple chemical sensitivities.

How do I explain what that one thing I need is worth? How this year I lay on a bathroom floor for about ten hours a day for seven straight months, with ants tracing Mercator lines across my belly, dying in the only spot to which I

could drag myself from my bed, because I was too weak to even crawl to my bedroom door to escape my room, as my father flew out from another state and then pathetically came into my bedroom for ten minutes but wouldn't do anything to help me, as I called Adult Protective Services because my mother was going to abandon me without care when I was choking for breath in some kind of severe respiratory failure, when I was unable to go to the hospital again due to MCS, when I spent months sucking on the end of a ventilator trying to save my life and could not get help. Adult Protective Services told me they could not intervene until significant harm had already been done to me by caregiver abandonment, and I had no way of medically proving how much harm had been done. My PCAs kept quitting and my friends were only able to offer brief care. At this point, I had such severe neurological and respiratory problems that I could not speak out loud, listen to any sound, endure touch or the presence of people, or reach a few feet to the end of my bed without increasing collapse. The specter of death felt terrifyingly near every minute.

In the years between those abusive relationships, I spent time engaging the world-at-large, begging everyone else for care, trying to find non-ableist allies when I could rarely leave my bed—then I returned, crestfallen, to the abusive people who were willing to offer what nobody else would provide. At some point in the interim, I would have a surge of idealism and energy for self-advocacy, trying to rally other sick friends to join with me in intentional community-building, researching a new treatment, maybe even luring my family out for a brief caregiving stint. In the end, I always ended up in the same place. Meanwhile, I had to face the social embarrassment of admitting I could not make anything else work, even though people with far more social clout have told similar stories. Pulitzer Prize–nominated writer Susan Griffin wrote about her terrifying search to find adequate care when she was very ill: "Night after night, thinking about how I would survive, as fear dissolved into anguish only to become panic again, I was afforded a vision beyond my private history into the nature of society itself. Over time these were the words that formed in my mind: They would have let me die."

So what does this mean on a social level? Lundy Bancroft writes, "Abuse is the product of a mentality that excuses and condones bullying and exploitation, that promotes superiority and disrespect, and that casts responsibility onto the oppressed," adding in a different chapter, "In short, the abusive mentality is the mentality of oppression." A person with disabilities must combat societal oppression at every turn in trying to escape an abuser, and sometimes that oppression feels more abusive, or at least more inescapable, than its intimate analogue, interpersonal abuse. Say a woman has a life-threatening heart condition that worsens if her heart rate becomes too high, and her rageaholic partner can inflict severe physical harm through prolonged yelling. Over two years, she goes from being semi-bedbound to totally bedbound from her partner's verbal abuse, yet she cannot get a restraining order because her partner never slapped or punched her. She tells an advocate that her partner did inflict bodily harm, in ways she might never recover from, but the advocate fixates on the heroic ways her partner helped her out after her last hospital stay. She talks about Munchausen syndrome by proxy (how a caregiver might harm a patient to gain positive attention for himself as the caregiver) and how her partner loved the attention, and asks if any courts in the state allow phone access, but she may as well be explaining chronic emphysema to an unmindful marathoner. The advocate finally concedes "emotional abuse" is "very real," and mentions the battered women's shelter is "working on" making one room disability accessible, but it's "not a funding priority." Her phone therapist says, "Well, you do have a degenerative condition—are you sure your partner made you sicker?" Meanwhile, she can't get up for a glass of water, and a simple phone call leaves her exhausted. She finally contacts her abuser because she needs someone to pick up a prescription. Her partner stops at the drugstore and rekindles the abuse cycle. It's not about flowers and chocolate: it's about meds that keep her alive.

IPV organizations have begun to address these realities of disability, but they rarely do more than cite statistical horrors (people with disabilities are at least twice as likely to be abused, a likely outcome in a society that consistently devalues the lives of people with disabilities) and impose an activist template that doesn't fit. Disability is treated as an afterthought, not something with dramatically different risks and needs. Many IPV organizations

are in fact performing oppressive acts of neglect and exclusion that mimic those of abusers, by denying access (not providing materials in braille, not installing wheelchair ramps, not enforcing strict fragrance-free policies) that effectively shut out disabled survivors and keep them locked in violence. Afraid or unwilling to confront their own ableism, these organizations rationalize the ways that disabled people are denied help, using a tired social argument that it's too hard, too expensive, or too embarrassing to ask others for accommodation requirements so that they avoid accountability for their marginalization of people with disabilities.

People from social service agencies frequently tell me that my disability would place unreasonable demands on everyone else, another stark example of ableism. Meanwhile I do see good ideas in the world, like the architectural concept of universal design—that is, housing design that would work for both the disabled and able-bodied. But the concept of universal design is not one that is typically applied to organizational structure, to the great detriment of the same people IPV organizations ostensibly serve. IPV organizations need to start looking at each facet of policy in terms of universal design. Class has been explored as a primary reason why women don't flee abuse (because they simply can't afford the escape or the life after), and disability also needs to be seriously considered. For example, during the tragedy of Hurricane Katrina in 2005, newscasters seemed flabbergasted that some people did not flee their homes right away because they could not afford transportation. Yet nearly half of those who died were 75 or older, which seems to indicate that physical ability might have been a pressing yet overwhelmingly overlooked issue, deeply conflated with race and class. With the epidemic reality of abuse toward people with disabilities (and seniors, who often share similar concerns), a "universally designed" set of IPV guidelines should be treated as a central issue.

In a culture that shuns and penalizes human vulnerability and provides at best an inadequate and spotty caregiving net, people with disabilities often rely on their abusers for food, bathing, toileting, transportation, and other survival needs. Many caregivers—not just partners—have intimate access to

the lives of people with disabilities. But leaving an abusive relationship can be imminently life-threatening because victims might lose sustaining care, and replacing this can be next to impossible unless there are non-abusive family members or friends willing to provide it. If IPV organizations don't understand the pressing need for transitional (or long-term) hands-on care, a disabled person will often not be able to leave. Most IPV literature erroneously attributes this literal dependency to "victim psychology" instead of addressing dangerous social depictions of people with disabilities as needy (and superfluous). If the only alternative to an abusive caregiver is institutionalization or worse, a disabled person may be weighing one bad option against another. Are four sterile walls better than an abuser who offers affection, money, or other perks? Not necessarily.

By and large, it is not Stockholm syndrome that holds a disabled person captive to an abusive caregiver, but material and often elaborate acts of physical deprivation and torture. When someone has a disability, these acts are easy to inflict (and obscure from the view of others): they may just be a matter of hiding someone's painkillers, or sabotaging his TTY (text telephone), or—most insidiously—becoming an indispensable aid so that he can't function without the provided care. Disabled individuals subjected to violence can't always just get up and go—an idea rooted in the ableist assumption that all people are unencumbered by physical restrictions. Whereas a safety plan for an able-bodied person may involve words like run, walk, call, or drive, these action verbs may not be possible for a quadriplegic, a heart failure patient, someone with a brain stem injury, or someone with cognitive impairment. It is naive to assume a disabled person can be ushered into a world of safety simply by leaving her abuser, when the world at large is full of physical, emotional, economic, cultural, and social barriers.

Typically, when interpersonal violence is committed against people with disabilities, it is handled administratively (that is, through social service organizations rather than through the criminal legal system). This reveals a disturbing and broadly held worldview: our society does not really view abuse of the disabled as a crime. Although many states have mandatory reporting

laws for abuse against people with disabilities, and social service personnel are legally mandated to report such abuse, few IPV organizations are familiar with these laws. And the court system is quite literally inaccessible. Several years ago, a woman contacted me because she was being regularly dragged down hallways by her hair and thrown against walls by a partner. I tried to convince her to get a restraining order, but this was immeasurably hard for her due to her anxiety disorder and extreme agoraphobia. She was multiply-disabled, but it didn't matter as far as the courts were concerned. When I asked a friend of mine who was also an attorney what it would take for the courts to accommodate a homebound person, she laughed and said, "Oh, they won't come to you unless you get a doctor's letter saying you're going to die very soon."

Later, I tried to get my own restraining order against one of the partners who was terrorizing me. Bedridden and homebound, I could not even make calls to advocates, who kept refusing to talk to my PCA on my behalf, probably because they assumed she was my abuser, and they couldn't imagine a disability hindering someone's ability to make phone calls. Finally they agreed to speak to my PCA, telling her there was no way I could get a restraining order without going to the courthouse unless an attorney filed a special motion on my behalf. Not only can I not travel, but I cannot go into facilities that are not fragrance- and chemical-free. It took my PCA about fifty calls (she estimates) to find an attorney who would do this. The attorney said time was of the essence as weeks had passed since my last contact with the abuser, and then she stopped returning our calls. I gave up in a state of complete despondency. I was extremely ill and couldn't even fight for appropriate medical care, let alone coordinate the changing of my locks or legal action against my partner. My helplessness wasn't learned: it was literal. Even lifting a phone receiver or talking into it required more strength than I generally had.

The West Virginia Coalition Against Domestic Violence reports that disabled victims are more likely to be blamed for their abuse, because they are perceived as difficult to be around or care for, and "caregiver stress" is considered a legitimate excuse for bad behavior. These social myths are no different from abuser jargon that habitually accuses those harmed of provoking

the abuse. Because of the subtleties involved in abusing a disabled partner, people with disabilities might not identify themselves as abused, and rarely receive support from a society that lionizes the abusive partner as self-sacrificing for dating crips. It is common for batterers to "target punch" their victims to avoid getting caught. With an able-bodied partner, this might mean hitting her torso where bruises will not show. With a blind partner, this could mean putting obstacles in her path so she will trip and fall. With a frail partner who is too neurologically impaired to deny consent, this could mean using body weight to hold her down during sex even while she tries to resist by stiffening her body and pushing weakly with her forearms, then forcing sex in a way that physically harms her. Batterers of able-bodied partners may target punch by punching a woman on her torso instead of her face, but they have still committed a crime recognized by the state; when battering disabled victims, physical harm can often easily be inflicted on a disabled partner without punching at all, and even with murderous consequences such cases are hard to prosecute. In one court case, a woman with MS was murdered by a caregiver who fed her a bagel, knowing she could not swallow on her own and would choke to death; in another case, a man with chemical sensitivities was assaulted by his former partner when she intentionally and angrily sprayed him with scented products to cause him physical injury.

Advocates working with disabled survivors must first redefine what constitutes IPV, tailoring their definition to an individual's disabilities just as the abuser has probably done. Abusers will often use the minimum amount of force required to maintain power and control, and this minimum amount of force used on a disabled person—though it may cause substantial injury—might not fit neatly into legal definitions of abuse. Coercion and threats to a disabled partner could involve threatening to withdraw basic support, an act that can be more dangerous to a person with a disability than a violent beating. Intimidation tactics might include harming or mistreating a service animal. Economic abuse might include embezzling funds from a disabled partner who can't fill out a deposit slip, or giving her lavish gifts of adaptive equipment the state won't pay for to encourage her dependence. Physical

abuse might consist of rough handling when transferring someone out of a wheelchair, or over-medicating. Sexual abuse might include forced abortion, inappropriate touching during bathing or dressing, or put-downs about a disabled person's sexuality. Neglect can include withholding care, medication, or life-sustaining attention. Many forms of abuse against people with disabilities, particularly those against some of the most vulnerable groups, such as the developmentally disabled, involve discrediting a person's own voice when she tries to convey her experience. Emotional abuse might take the form of denying the person's feelings by attributing injuries to the disability itself ("You're just touch-sensitive! That didn't hurt.").

Activists need to remain alert to the creative ways abusers cover up their violent behavior and get away with it. Key to an abuser's ability to manipulate friends, therapists, social workers, and the court systems is the still underexamined reality of societal ableism. Abusers sail through life, therapy, and the court system with a "not as bad as that guy" philosophy. They routinely rationalize their behavior, and can often pass off controlling behaviors toward a disabled partner as "concern." If they can convince themselves or others that looking through a partner's garbage, monitoring his phone calls and mileage, and insisting to know what he does every waking hour is not abuse and is instead a form of worry or concern, they will. The "worry" excuse is a particularly effective tactic when used by abusers of the disabled, since frequent checking on a disabled partner (and depriving her of freedoms in the process) is so socially acceptable: plus, she may need someone to check and make sure her wheelchair ramp has been cleared of snow, or to confirm she has food in the house. For a disabled person confined mostly to a home or bed, such acts of control both mirror and amplify the inherent suffering created by the disability in the first place. Most people will believe the abuser's pleas that she was simply trying to protect her (ungrateful, in society's view) disabled partner.

At every turn, society is complicit in the abuse of disabled people. For example, an abuser will seek to isolate his partner. If that person is wheelchair-bound, and very few venues in town are wheelchair-accessible, the abuser is not the only one isolating her: society has shut her out by relinquishing

responsibility for accommodation. When she comes forward with her abuse, her peers might side with the abuser because they are, through inaction, supporting and privileged by a similar agenda. When the abuser talks about all he has done for his victim, as abusers are prone to do—and the list includes bathing her, driving her to medical appointments, and hand-dispensing medication—people might view him as a hero. This too reflects the deep threads of ableism in US culture, which forwards the belief that basic, hands-on care for most disabled people is exceptional and heroic, and should not be socially mandated.

Without a social philosophy that frames care as everyone's duty, society participates in a "slow code" ethic toward the disabled. ("Slow code" is a term used among hospital workers to denote the practice of only giving futile, going-through-the-motions resuscitation to some patients whose lives are considered too impaired to be worth saving.) A society that abandons people with disabilities, giving them few care options and tacitly accepting their abuse, simply will not adequately punish the same abusive caregivers who provide the care it refuses.

While capitalism, narcissistic cultural values, and other forces create care gaps, this care problem can't be plugged into a simplistic cultural analysis. Due to what many attribute to traditional family values that demand respect for seniors, for example, Japan shows signs of outpacing the US in creating a humane and innovative care system. In some areas, active members of society can "pay in" to a collective care system called "Koreikyo" by volunteering to care for frail members of society, to get "credit" for care when they need it, and the Japanese government has heavily funded robotics scientists who are working on caregiving robots to assist the elderly and disabled with such things as transfers (from bed to a wheelchair or bath) or vital signs monitoring. Despite these innovations, there is a Japanese term, kodokushi, or "lonely deaths," as so many uncared-for seniors now die alone, leaving human-shaped stains as they decompose and often are not found for long periods of time.

This idealized, sometimes robotic (literally) approach to care is what I call a cortical (higher brain) solution to a limbic (emotional/fight-or-flight

brain) problem. Academic approaches around disability can easily become too robotic, pulling activists away from the shadowy realities of physical survival that haunt most disabled folks. A robot will never combat a problem as vast as social isolation or the horror of dying alone, nor will one lone gesture from an IPV organization to provide TTY access on its hotline help a person who is trapped in a rural setting, homebound, and living with late-stage AIDS. Additionally, a caregiving system will not actually make people care, and the problem with caregiving systems in general is that they easily become sterile/neglectful, or abusive, themselves, which is evident in the horrifying statistics of abuse in nursing homes. The human response must be deeper than that. Just as Lundy Bancroft argues that the abusive mentality is the mentality of oppression, I would argue that the Darwinian response to disabled folks (abandon the weak) is in fact the mentality of oppression, and people must be constantly challenged to question this way of thinking.

In an ableist framework, people often conflate disability empowerment with taking a "just like me" attitude that presumes a disabled person wouldn't want exceptional treatment—even if that treatment is a fragrance-free accommodation or a sign language interpreter, or, more subtly, acknowledgement of physical vulnerability. The differences in human vulnerability can be huge, especially when talking about IPV dynamics that involve power and control. Ignoring this fact denies the reality of people with disabilities and reinforces a mentality that only wheelchair athletes and feel-good supercrips should be recognized. Understanding the intricate differences in people's physical power and ability enables activists to calibrate their definitions of abuse. While the abuser of an able-bodied person might bar her exit by pushing furniture in front of escape routes and pulling phone cords out of the walls, the abuser of a bedridden individual can subtly inflict the same level of terrorism by simply charging into a bedroom and screaming when she can't get up and leave. It is critical that anti-violence movements in particular understand and treat such acts as equivalent. It can be enormously invalidating for a disabled abuse victim to hear, "I would just leave if someone treated me that way!" Or even, "I would just ask the abuser to leave." Asking an abuser to

leave is often not an option for someone with a disability: she might need him to take care of her after he battered her. And who is going to explain to the hospital staff the medical needs relating to her rare congenital condition? My PCAs, who rarely keep the job more than a few months, could not describe my mitochondrial damage or dysautonomia or intricate hypersensitivities to an EMT, and this could mean the difference between life and death.

What often endears a batterer to a disabled person is her investment in the disabled person's vulnerability and his acquired knowledge about her condition, which most of society insults, ignores, and doesn't respond to in an empowering way. All abusers are dependent on keeping their victims vulnerable, a fact that transcends disability. When disability is involved, abusers put this attunement to the power imbalance toward monitoring what a disabled person needs, and then how to give or withdraw what is needed to gain power and maintain control. And more often than not, other able-bodied people just stand by and don't offer help. Few people know the intricate ergonomics of a disabled person's life, even though her ability to function—and survive—depends upon this knowledge. Ironically, abusers come to intimately understand this same complex reality that most people do not notice or care about. For years I tried to explain to my family why I needed someone to be on call 24 hours a day due to my erratic medical emergencies, to bring me food and water while I was lying down unable to move, and to nurse me during the unpredictable crashes I suffered following a chemical exposure or over-exertion. In response, they offered inconsistent bursts of help and care—a week here and a few days there—assuming (or hoping) that someone "out there" would fill the long gaps in between. But there was no one, no one but an abuser carefully tuned to my vulnerabilities. While others in my life would try to create a cheerful mood and occasionally bring me take-out, my abuser would dig into the gritty realities of my disability, draping a blanket over my legs before I even said I was cold, bringing me a glass with a straw so I could drink lying down. These were the acts of kindness woven into the abuse, and without them I would not have survived. Other people were willing to show up here and there, but my abuser craved the traumatic bonding of weathering my illness up close. This isn't to excuse the abuser's heinous

behavior, but to point out that until people have access to the resources that can help them live healthy, functional lives, they will remain easy prey.

The details, in other words, cannot be afterthoughts. Wheelchair ramps, phone access, and other accommodations are essential for disabled survivors to make the first move toward escape. Abusers tend to look for social cues to tell them whom they can most readily victimize. As a critical step in ending abuse, IPV organizations must prioritize educating their staff and building their policy and practices around disability, and include the voices of people with diverse disabilities in that education process. Extensive planning must go into making sure services are accessible before a person with a disability calls; when stopping abuse, time is of the essence. And no one should have to beg for access. Meanwhile, more and more IPV survivors are becoming disabled. It is not uncommon for initially able-bodied victims of IPV to become temporarily or permanently disabled by physical injuries inflicted by abusers, or to develop ongoing psychiatric disabilities caused by the abuse. A study published in the *Journal of General Internal Medicine* found that domestic violence survivors have higher health care costs than other women for three years after the abuse ends. Survivors of IPV who develop new disabilities are at risk of entering relationships with new abusers who may then use the additional disability against them, or incorporate it into abuse strategies. The underpinnings of abuse have to do with distorted notions of strength and weakness, with the essence of bullying.

IPV activists must ferret out inequities in their own organizations to take a concrete stance against the exploitation of able-bodied privilege. Disability is a central issue in ending IPV. Organizations must start with full, unapologetic access for all people with disabilities. Access should include creative solutions such as Skype or phone access for those who are homebound. Where different disabilities have contradictory needs (for example, putting in a wheelchair-accessible bathroom may involve toxic building products that could harm a chemically sensitive person, but both needs can be recognized with the help of a green building consultant who understands universal design), able-bodied activists have to think beyond the ableist notion of compromise. People with

disabilities cannot compromise their disabilities, so access must be fully realized. Second, IPV activists must ask themselves in challenging and perhaps uncomfortable terms how they view "reasonable accommodation." Who are they shutting out by rationalizations of what they deem reasonable, and why is this acceptable to them? Third, a radical social revisioning of care must include the willingness to take radical action. IPV activists must ask: if an abuser is committed to offering care for the next five years, who is going to replace that? Many shelters provide childcare and even pet care, but I have not heard of one providing care for the disabled. So what I am proposing is the radical notion of doing what is needed. Oppression is what is unreasonable, and seemingly unreasonable barriers must be conquered. This truth must serve as a basic mantra for activists looking at ableism.

As activists, many of us put a cap on our benevolence that distracts us from what is sensible. One time, while waiting for a bus in Berkeley, a woman approached me. She said she was trying to leave an abusive husband and needed money for bus fare. I only had twenty dollars in my wallet but, sensing she wasn't scamming me, I offered it. She said it wasn't enough, and tried to convince me to go with her to the ATM but I refused. She handed the twenty back. "It's too late," she said despairingly. "The fare is twenty-seven dollars and my husband is getting home from work and will see I'm gone. I have to go back home." She did not reach for my money again. IPV organizations have to understand the literalness of that extra seven dollars, both in terms of poverty/class issues (which are epidemic among the disabled as well as able-bodied IPV survivors), and in how it applies to disability, and they must find ways to bridge the seven-dollar gap that often excludes so many people. The first question an IPV organization needs to ask a disabled person is, what are your needs? Then, it is important to see the difference that seven more dollars, or a ramp, or fragrance-free access, or another accommodation that goes all the way, can make.

IPV organizations and activists need to carefully examine their stereotypes about violence, and constantly work to bring disability into the conversation.

Identifying an abuse dynamic always has challenges, and with disability there are unique issues. A seemingly combative person with encephalopathy may appear angry yet still be dealing with caregiver abuse. A deaf abuser may yell with his hands. People may perceive a disabled person as being a demanding bully and an abusive caregiver as a victim simply because she is moaning piercingly in discomfort and needs assistance.

In terms of broader activism, anti-racist organizations might look at the long, troubled history of eugenics activities that have almost always targeted people based on both disability and race, and how these have advanced other forms of violence. Queer organizations should consider how much they have to learn from those whose bodies have been historically loathed for their queerness. Disability is a common cause of homelessness and poverty, and should be included in discussions about these issues. Prison reform and abolition work must include an analysis both of how disabled prisoners are treated and cared for, but also how prison conditions create disability—for example, how solitary confinement is a physically disabling form of torture, since research shows it may cause organic brain changes and psychiatric damage.

Lastly, IPV workers must all be trained on disability-sensitivity and challenged to confront their ableism by always keeping an eye for inclusion. The ability to convey the gestalt of a traumatic experience to a receptive witness, and validation that truly comprehends differences in vulnerability, is crucial in aiding IPV survivors to step out of the fury and into a safe future.

works cited

Lundy Bancroft, *Why Does He Do That? Inside the Minds of Angry and Controlling Men* (New York: Berkeley Trade, 2003).

Paul A. Fishman, Amy E. Bonomi, Melissa L. Anderson, Robert J. Reid, and Fred P. Rivara, "Changes in Health Care Costs over Time Following the Cessation of Intimate Partner Violence," *Journal of General Internal Medicine* (2010): doi:10.1007/s11606-010-1359-0.

"GeckoSystems' Elder Care Robot Trials' Caregiver Praises New GeckoSchedulerTM," *Green Technology*, http://green.tmcnet.com/news/2010/06/10/4838502.htm.

Susan Griffin, *What Her Body Thought: A Journey Into the Shadows* (San Francisco, CA: HarperOne, 1999).

Robert C. Marshall. "Koreikyo: A Japanese Home Care Co-op Run For and By Seniors," *Grassroots Economic Organizing*, http://www.geonewsletter.org/node/147.

Justin Nobel, "Japan's 'Lonely Deaths': A Business Opportunity" (April 6, 2010), http://www.time.com/time/world/article/0,8599,1976952,00.html

Judith Wallerstein, Julia M. Lewis, and Sandra Blakeslee, *The Unexpected Legacy of Divorce: A 25-year Landmark Study* (New York: Hyperion, 2001).